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ABSTRACT

Presented is the manual which resulted from a project to develop a program of relief or respite care for families with developmentally disabled members. Background on the respite care approach in Montgomery County (Maryland) is reviewed, and a long range and immediate goals of the project are outlined. Noted among results of a survey to determine current relief care practices of families are that the demand for vacation care is heard more frequently from parents of adults than from parents of younger children and that most families do not want to exchange sitting with other families. Reviewed are meetings held concerning survey results, directions to take in addition to training of home care services caregivers, and plans of action. Presented are a working paper on the home and community resource program (which includes sections on funding sources, definitions, and implementation of service areas) and a mock bill requiring that a percentage of beds in state institutions be reserved for respite care. Listed among staff observations is that providing respite care alternatives need not be expensive. Appended materials include a list of coalition members, a copy of the child care survey, survey results, training session agendas and a copy of the respite care coalition evaluation questionnaire. (SBH)

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A COALITION APPROACH

TO

RESPITE CARE

by

Cory Moore, Coordinator

Montgomery County (Maryland) Respite Care Network Coalition

1976 - 1977

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RESPITE CARE ..... WHAT IS IT?

Respite care -- short-term, temporary care of a family member with a disability

Respite care -- an interval of time that allows a family relief from its daily routine

Respite care -- a vital supportive service; an aid in keeping families together; a well-deserved necessity

THE BEGINNINGS

The Coalition approach to respite care began with the concern of Peg Morton, Director of Family and Community Services of the Montgomery County (Maryland) Association for Retarded Citizens, who is herself the parent of a profoundly retarded child. It started with a realization that of the thousand calls received in the course of a year by her Family and Community Services office, an information and referral service, over one-third focused on the need for some form of relief care: discussions of unobtainable residential placements, appeals for a well-trained caregiver required because of a sudden emergency, requests for understanding baby sitters to allow a family some time away or a parent some time alone. The voices of the people calling were often tired-sounding, concerned, strained. The absence of relief care options available to them were all too apparent.

If statistics can be trusted, one out of every ten families has a physically handicapped, mentally retarded, or emotionally disturbed member with special needs. In most of these families, the handicapped child or adult places an extra burden of care on mothers, fathers, brothers, and sisters.

When a child, because of mental or physical limitations, is unable to set up activities and provide amusement for himself,

When friends live miles away rather than around the corner because they go to special schools,

When siblings have--as they should--their own friends and activities to engage them,

the unending responsibility for care, encouragement, training, and daily life routines all falls on parents already carrying heavy burdens and often lacking the time, the energy, and the inclination to set up supportive systems not easily accessible. With little relief from daily responsibilities, frustrations, feelings of isolation, physical and psychic fatigue steadily mount.

But relief from the daily routine is vital for everyone to maintain positive mental health: all people need a chance for renewal, a time for being alone to regain

perspective, composure, and humor, and -- in the particular case of families with disabled members -- a chance for husband and wife to know each other as people and not just as parents of a handicapped child. Revitalization is imperative, "normalization" for parents and siblings of the handicapped is a necessity.

FAMILIES NEED .....

Rest

Relief

As normal a way of life as possible

The freedom to socialize

A time to relax

And what of the child with a handicap?

Learning to get along with a variety of adults is an important part of any child's upbringing. Often the child with a disability has fewer contacts outside of his home and is far more isolated than his nonhandicapped peers. Opportunities, therefore, must be created for him to learn to know and trust others. The child with a handicap is being denied an important and essential growth experience if his family does not allow him the chance to be with other competent, caring people.

THE CHILD NEEDS .....

A chance to grow

An opportunity to learn

A means of establishing trust

An identity beyond his immediate family

Respite care cannot be considered a luxury; it is a necessity if families are to stay together and function well together. Parents deserve relief from their daily responsibilities; their handicapped children must learn to know and trust people outside their immediate families. The long range effects of this supportive service can only produce happier, freer, and less anxiety-ridden people.

REMEMBER!

TIME AWAY FROM ONGOING RESPONSIBILITIES IS ESSENTIAL FOR PARENTS.
CHILDREN NEED EXPERIENCE IN RELATING TO OTHER ADULTS

THE RESPITE CARE COALITION

The recognition, then, of a problem needing creative solutions came first. A proposal was submitted by the Montgomery County Association for Retarded Citizens (MCARC) Family and Community Services department, to the Maryland Developmental Disabilities Council. It asked for a modest amount of money to fund the setting up of a coalition as the vehicle for assessing needs of families with handicapped members and planning a menu of services for these families. It called for the hiring of a half-time respite care coalition coordinator, the planning of a survey to determine current relief care practices of families, the conducting of the survey, the arrival by the coalition at recommendations for services to be offered families, the preparation of an information packet on respite care and other supportive services for families, the preparation of a manual on the coalition approach to planning respite care services [the same manual you are now reading], and the mobilization or adaptation of existing generic services to extend to families with severely disabled members. Its stated goals were as follows:

Long range goals:

a). To provide the best quality of respite care options for families with developmentally disabled members.

b). By providing such alternatives, to reduce the chronic stress experienced by families of children with severe disabilities which so often leads to premature or unnecessary residential placement.

Immediate goals:

a). To develop a program which will help us and our fellow parent organizations, as well as concerned agencies, to understand the dimensions of respite care uses and needs of the wide variety of families of developmentally disabled children in Montgomery County; to determine if and how families are currently getting the relief care they need or wish; to know what kinds of care would interest them and to plan who should provide the alternatives indicated.

b). To use the coalition approach for the planning and ultimate implementation of options which might provide more families with more opportunities for a more normalized way of life.

c). To establish the continuing viability of such a coalition for the planning, provision and coordination of other services which involve the substantially disabled--persons who generally are not easily incorporated into the service system which is responsible to the general population.

But even before the proposal was funded on July 1, 1976, work began on the respite care network, largely out of a determination to get something started even if no money was forthcoming.

A tentative draft of a "needs assessment" questionnaire was designed by MCARC Family and Community Services. A meeting was planned. In January, 1976, a group of people, representing both the principal county (and state, as appropriate) agencies concerned with human services and the Montgomery County organizations of parents of children with developmental disabilities, were contacted. The draft questionnaire was sent to them along with an invitation to join in a concerted, County-wide effort to learn about the current practices of families with a disabled member and--

with insights gained from a survey--to plan new services, improve and expand what already existed, and coordinate it all so that families would be less adrift in their efforts to cope. This working coalition, then, would serve as a vehicle for assessing the need for respite care, for planning a network of relief/respite care services, and for cooperatively implementing such a network.

AGENCIES AND ORGANIZATIONS REPRESENTED
(see Appendix A, p. 23, for names of Coalition members)

- Great Oaks Regional Center for the Retarded
- Mental Retardation Administration, Montgomery County Continuum of Care Coordinator
- Montgomery County Community Coordinated Child Care Council
- Montgomery County Department of Health Systems Planning
- Montgomery County Department of Social Services
- Montgomery County Health Department
- Montgomery County Office of Human Resources
- Montgomery County Public Schools, Division of Special Education
- Montgomery County Recreation Department

- Association for Children with Social and Emotional Problems or Troubles
- Centers for the Handicapped
- Montgomery County Association for the Advancement of the Physically Handicapped
- Montgomery County Association for Children with Learning Disabilities
- Montgomery County Association for Hearing Impaired Children
- Montgomery County Association for Retarded Citizens
- Montgomery County Chapter, National Society for Autistic Children
- Montgomery County Mental Health Association

PURPOSES FOR GATHERING

- Because the Montgomery County Association for Retarded Citizens has for some time been concerned about the absence of relief care options for families who are keeping their mentally handicapped children at home, often under great stress
- Because of the Association's awareness that crises occur, everyone needs a vacation, and everyone needs an occasional break from the demands of care of a handicapped person, even under the best of circumstances
- Because the Association knows families with retarded members need more help than they are getting and suspect the need is a common one for families with a disabled member of any kind

The response was unusually gratifying. Invited members responded to the letter and the draft questionnaire, some in advance of the first meeting of the Coalition, others at the meeting. Respite care was obviously a need well-recognized, an idea whose time had come, and the wish to help in its implementation attracted a large turnout to the first meeting in late January, 1976, of the Montgomery County Respite Care Network Coalition. Discussion centered around the use of the questionnaire as an acceptable method of assessing family needs, how the questionnaire should be distributed and by whom, what is currently available to families in Montgomery County, and whether a coalition of organizations and agencies is a viable vehicle for planning a "menu of services" for families with a disabled member.

The consensus was that the Coalition approach was indeed workable. The practical considerations of staffing the survey project were met by the group agreeing to have Peg Morton serve as Project Director, and Donna Holt, MSW, a MCARC consultant who had helped develop the original needs assessment questionnaire, be in charge of conducting the survey itself. A small subcommittee of the Coalition met to redesign the questionnaire which would determine current child care practices of families of children with developmental disabilities. It was to be a product of the Coalition thinking expressed at the January meeting.

THE SURVEY

The survey went through several revisions; its final form is in Appendix B, pp. 24-26. With approval of the Respite Care Coalition members having been solicited by mail, the survey was used by Donna Holt as the basis for telephone and face-to-face interviews of families with handicapped members. The families were selected by six parent organizations in Montgomery County, all represented on the Coalition--The Montgomery County Association for Retarded Citizens, the Centers for the Handicapped, the Association for Children with Social and Emotional Problems or Troubles, the Montgomery County Association for the Advancement of the Physically Handicapped, the Montgomery County chapter of the Society for Autistic Children, and the Spina Bifida Association--and included 50 children of various ages from preschool through adult, and various kinds of handicapping conditions, most of which were severe. Twenty-five of the children were described as retarded, twelve as physically handicapped, five as severely multiply-handicapped, and eight as emotionally disturbed or autistic.

The cover letter which had gone out with the survey (see Appendix C, p. 27) explained to the families interviewed that a Coalition had been formed to draw up a survey to help relieve what was felt to be a shortage of help for families with handicapped members; it asked for information which would help the study reflect the true needs of the families in our community. The hope was expressed that the information gained from the survey would be used to improve and expand present child care services and to plan new services based on the needs of families. Anonymity was assured.

The results of the interviews were presented to the Respite Care Network Coalition on its first gathering after Developmental Disabilities funding had been approved. The meeting took place in July of 1976 and was actually the second meeting of the full Coalition membership.

The full survey results can be found in Appendix D, pp. 28-30. For our purposes, a summary follows of the main points of information learned from the interviewed families.

1. Care in the home is the most commonly used and preferred form of care. The principal sources of care in the home are siblings, untrained sitters, and neighbors or friends.

2. The use of care outside the home is episodic or occasional. What to do in case of illness or emergency is a great concern for all families, but especially for parents of adults.

3. The demand for vacation care was heard more frequently from parents of adults than from parents of younger children. Most families adapt their vacations to their children or are restricted to vacationing separately if their children are at camp.

4. Some families just do not go out. As the children grow older, use of sitters is less frequent. Families with physically handicapped children are affected earlier and tend to go out infrequently from the start. If families do go out, they commonly take the child with them.

5. Most families do not want to exchange sitting with other families.

The survey results demonstrated all too plainly that most families have adjusted their thinking, their homes, and their lives to their handicapped children. Trips are planned around the needs of the handicapped child or families do not get away at all. Siblings, and to some extent friends and grandparents, commonly provide respite for parents; but, as the only solution, this practice can itself set up feelings of obligation and/or guilt that may create additional strains.

Some families interviewed for the survey commented that they did not want their handicapped child singled out as being different from his siblings when it comes to child care. But the fact is that the handicapped child is different in his needs. In accomodating them, many parents give up pleasures for themselves and deny siblings activities that other families are free to engage in. Spur-of-the-moment family outings are rarely possible; special food or equipment for the handicapped person is often needed; medical emergencies must be carefully planned for. Movie theaters and restaurants must be checked in advance for accessibility to wheelchairs. Recreational possibilities attractive to typical children often hold no interest for mentally handicapped children.

DIRECTIONS

A discouraging picture emerged from the survey and other reports at the July meeting of the Respite Care Network Coalition to confirm what was already suspected: few services existed and those that did could not serve the wide and unique needs of individual families; community care and support care were not available; sources of relief care were not increasing as the demand increased; Great Oaks--the Regional Center for Retardation that serves Montgomery County--

could offer respite care only when children in permanent placement at the institution were taken home for weekends or holidays and the cooperation of families in so doing had been and was continuing to be minimal and discouraging; no foster care homes existed for handicapped children or adults; no special training in the care of a handicapped child was available in the Family Day Care or Foster Care programs run by the Montgomery County Department of Social Services; DSS Homemaker Service was available to families with handicapped members but staff was limited and emergency response was not possible.

One private, non-profit service, a necessary item on any "menu" of relief care alternatives, did exist. It was called Home Care Services for the Handicapped. Home Care Services had been organized in 1972 by Rosalie Iadarola, the mother of a handicapped child who recognized the need for respite care and determined to meet the need. Dedicated to providing short-term, temporary respite care by trained caregivers, Home Care Services had run successfully for four years with two small grants from the Cafritz Foundation and the Public Welfare Foundation funding its operation. But the director of the service could no longer continue her role and no replacement was forthcoming. Furthermore, the grants for the program were not renewable for much longer. So at the same time the Montgomery County Respite Care Network Coalition was in the process of being organized, the Montgomery County Association for Retarded Citizens became the sponsoring agency of Home Care Services, with a one year limitation set by its Board of Directors, in order to keep alive this vital, parent-run service which was suddenly in danger of collapsing. The Respite Care Network Coalition members were pleased to learn of the continuation of Home Care Services for the Handicapped, the obvious bedrock of any network of respite care options. They met its newly-hired Coordinator, Cindy (Beck) Love, and learned of her procedures for recruiting, interviewing, and supervising caregivers, and for responding to families' requests for respite care.

At the same July meeting, in response to the survey results, a thoughtful discussion ensued among the Coalition members. First, the group consensus was that a larger, County-wide survey would not yield substantially different information from that already gleaned and would consume time and energy better utilized implementing recommendations based on the pilot survey and on the perceptions of needs by the assembled agency and organization representatives. The Coalition decision, therefore, was to develop as many of these recommended services as quickly as possible. The original grant proposal, as outlined earlier, was amended to reflect the feeling of the group and was subsequently accepted as amended by the Developmental Disabilities Council. The new thrust was to provide more aides for care in the home; develop good, specially trained and supervised out-of-home respite and day caretakers for children and adults with disabilities; provide orientation and training for daycare and foster parents already on the roster of the Montgomery County Department of Social Services as childcare providers; and to educate parents about the long-range benefits of utilizing respite care.

The Montgomery County Respite Care Network Coalition accepted Cory Moore of the MCARC Family and Community Services staff as the Respite Care Network Coalition Coordinator; Peg Morton would continue to serve as the Project Supervisor.

A number of possible directions in addition to the training of Home Care Services caregivers were talked about: the possibility of a group home for respite care which could serve several populations--elderly people, child welfare recipients, people with physical handicaps, foster children who were between placements, foster families in need of a respite service for their foster children. The Coalition discussed the possibility of a sheltered facility with medical back-up as a joint concern of two agencies. Other needs the Respite Care Coalition focused on were after-school care for developmentally disabled individuals; out-of-home programs

for handicapped adults; a training residence for people with physical handicaps; weekend and vacation respite care using summer rental facilities; parent sensitivity groups to help parents learn to ask for help; the necessity of raising the consciousness of the community about its developmentally disabled members; the recruitment of graduate students to work directly with a family with a developmentally disabled member, possibly as an independent study project.

And so the program "Respite Care Network: Options for Families" began. Clearly, there were many directions that could be taken, many decisions to be made. The basis for future determinations by the Montgomery County Respite Care Network Coalition had to begin with the open-ended notion of the need for a variety of services to be delivered in a flexible fashion according to individual needs. For just as the needs of handicapped children are unique, so are the needs of their families.

First steps taken by the Respite Care Network Coordinator following the July Coalition meeting were to set up a variety of meetings and contacts as well as to collect and pursue leads on any information regarding respite care throughout the country.

. Members of the Respite Care Network Coalition were consulted individually during the next weeks to further learn their concerns and tap their personal and professional knowledge.

. The Supervisor of the Department of Social Services Day Care Licensing was approached for information concerning licensing procedures.

. The Department of Social Services day care and foster care social workers were introduced to Home Care Services for the Handicapped and the respite care network of options.

. Meetings were held with day care mothers, newly recruited foster parents, and the staff of the three public schools serving moderately retarded children to explain families' need for respite care.

. The president of the Montgomery County Foster Care Association was asked for help in seeking foster families to provide homes for children with handicaps on a short-term basis.

. Contacts were made with colleges and universities.

. An initial training session for Home Care Services for the Handicapped caregivers was planned; two members of the Respite Care Network Coalition took part as speakers in this first training session. All members of the Coalition were sent information regarding the training session to circulate as they saw fit. Several Coalition members showed their interest by joining the audience of caregivers on the day of the session. (See Appendix E, pp. 31-35, for the agenda of this and subsequent training sessions.)

. An information sheet on "Places to Call for Child Care" was compiled and circulated to parents of developmentally disabled children.

. A fact sheet listing what other states are doing about respite care was written. (See Appendix F, p. 36.)

It became increasingly evident during these early weeks that there were many advantages to a specialized clearing house which would coordinate respite care for

families, as Home Care Services was currently doing, and that a successful network of alternatives for respite care would require two capabilities to function well; the ability to respond to parents' requests for the various kinds of child care they might need, be it hourly, weekend, vacation or crisis service; and the ability to recruit, train, and provide ongoing professional backup to caregivers of every variety--foster parents, day care mothers, aides to work in the home, homemakers, students, etc.

The Montgomery County Respite Care Network Coalition reconvened on November 30, 1976, this time to hear about the progress in already charted areas and to discuss further the network's options. It was generally agreed at this meeting that Home Care Services for the Handicapped was a necessary concommitant of a respite network that could not be allowed to die at the end of the year for lack of funding. Members of the Coalition were also in strong agreement that the generic service system already providing child and adult care programs for nonhandicapped persons should assume responsibility for the handicapped members of the community as well. Consequently, a subcommittee was formed to write up a program for subsidized respite care, family aid, homemaker services and day care under the administration of a single community agency.

At the same November meeting of the Coalition, Harriet O'Connor, a parent of a profoundly retarded and physically handicapped child, who had been invited to join the Coalition after approaching MCARC with her concerns, spoke of her distress over the lack of respite care available at the regional center for retardation, Great Oaks. The Coalition heard a very personal, but typical plea for a place families could seek respite care for vacations, for emergencies, for crisis situations--a place equipped to handle a retarded child in need of trained medical backup. A decision was made that the subcommittee mentioned above would also work on a bill to be submitted to the Maryland State Legislature which would mandate respite care beds in state institutions under the jurisdiction of the Mental Retardation Administration. (Although this service would be available only to the retarded population, it was decided by the Coalition that this would be an appropriate first step in securing respite care services for all persons with handicaps.)

It was felt by the Coalition that the passage of such a bill would provide families with the support which could prevent, or at least postpone, the need for permanent residential care for their disabled member. A mandate to reserve beds could offer temporary help to families in crisis or when emergencies arise. Reserved beds might make it possible to offer regularly scheduled respite care to families to help normalize their lives.

It was clear at this point that there were numerous options open and a number of directions that the Coalition could take in an area as broad as that of respite care. Any of the numerous projects discussed at the first meetings of the Coalition would have been valuable and important possibilities to pursue. Several of them were investigated and preliminary steps were taken. Ideas are never at a premium in a group of thinking, concerned people but energy must be marshalled into workable channels if anything is to happen beyond preliminary investigations. The chosen directions for our Coalition, then, were to make Home Care Services in some way a part of the generic service system, to continue to train Home Care Service caregivers to assist families with handicapped members through the grant year, and to legislate respite care beds in the state facilities under the jurisdiction of the Mental Retardation Administration. In addition, families with developmentally disabled children were to be offered at least one opportunity for group respite care--either after school or over a weekend--during the grant year.

RESULTS

A COMMUNITY RESPITE PROGRAM

The subcommittee of the Montgomery County Respite Care Network Coalition met several times in the month of December; their teamwork resulted in (1) "The Home and Community Resource Program: A Working Paper" which was in large measure inspired by a program administered by the Pennsylvania Office of Mental Retardation/Mental Health to provide any service necessary to a family to enable them to keep their retarded child at home, and (2) a mock bill requiring that a percentage of beds in state institutions be reserved for respite care.

HOME AND COMMUNITY RESOURCE PROGRAM: A WORKING PAPER

General Statement:

Persons with substantial mental, emotional, or physical handicaps have, in the past and on into the present, been excluded from many of the social services offered to the non-handicapped population. The purpose of the Home and Community Resource Program is to make needed supportive services available to disabled children and adults, specifically to help in achieving the following goals: To help families stay together; to help individuals achieve or maintain self-sufficiency; to reduce or prevent dependency; and to postpone or prevent the need for institutional care by providing community-based care, home-based care, and other forms of less intensive supportive services.

Home and Community Resource Program -- Purpose:

The Home and Community Resource Program is designed to offer a variety of services to the family with a disabled member or members under the administration of a single agency, the Department of Social Services, which already provides a number of such services to the general population.

The primary purposes of the Home and Community Resource Program are:

1) to provide adequate resources within the community to enable the family with a mentally, emotionally, or physically disabled member or members to maintain that member or those members at home with a minimum of stress or disruption to the family unit and thus to prevent or at least postpone the need for institutionalization or other forms of permanent residential care.

2) to provide adequate resources within the community to enable disabled individuals to live in the community as independently as possible.

3) to provide the opportunity for the primary care giver to pursue employment if desired.

Eligible Population:

Family: Natural or adoptive parent(s), foster parent(s), related or unrelated persons who are responsible for the care of a disabled child or adult (such as siblings or guardians).

Individual: Any child or adult, no matter how severe his disability or combination of disabilities.

Possible funding sources:

(For Discussion)

Determination of Liability:

Under the Home and Community Resource Program, services will be provided without cost to recipients of Aid to Families with Dependent Children or Supplemental Security Income. The liability of others for services rendered will be based on income criteria established by the Department of Social Services.

Charges:

The charges to clients and legally responsible relatives for services provided by the Home and Community Resource Program shall not exceed the maximum which is an appropriate charge for a family earning 115% of the State's median income.

Service Areas:

The Home and Community Resource Program offers a range of services that are provided both within and outside of the home by a variety of agencies and persons.

Definitions:

1) Respite Care: This is a service which offers a period of relief to persons who have a disabled member or members living within the home. It would include care of the disabled child (children) or adult(s) for a period of between 24 hours and 4 weeks, a) in the disabled person's own home; b) in the home of a licensed or approved temporary foster parent or family; or c) in an approved medical facility for those persons requiring medical supervision.

2) Family Aid: This is an intermittent "sitting" type service providing relief lasting less than 24 hours, within the disabled person's own home or in the home of a DSS licensed and approved person.

3) Day Care: This service provides daily before-or-after school care for disabled children or full or part-day care for dependent disabled adults so their parent(s) or permanent caretakers can pursue education, job training or employment. It can take place within the home of the disabled person or in the home of a DSS licensed and approved person.

4) Homemaker Service: This service provides homemaking and housekeeping services (cleaning, cooking, meal planning, budgeting, marketing, etc.) in addition to care and supervision of the disabled person(s) and other family members within the home when responsible adults are unable to provide care and household management. The service also provides training in proper home management where these skills are lacking.

Service Areas, Implementation:

I. Care Registry: A central source of assistance within the Department of Social Services for families with disabled members or for disabled individuals in obtaining various kinds of child or adult care (hourly, weekend, vacation, crisis; in-home, out-of-home, homemaker help, etc.). The Registry Coordinator will have the capability of responding to family's or individual's requests for care by procuring appropriate services within the Home and Community Resource Program as described below, within current Department of Social Services programs, or by referral to agencies outside DSS which provide services. Essential to this function is follow-up to assure that the family or individual has obtained the assistance needed.

The Care Registry will maintain a listing and file of necessary forms and records concerning all trained and approved persons (Respite Care providers, Family Aides, Homemakers, Day Care givers) as defined above. The Care Registry Coordinator will coordinate follow-up training and support for all care givers.

The Care Registry Coordinator will maintain a listing and all necessary forms, releases, etc. concerning all families or individuals requesting care. Rules of confidentiality and privacy will be observed.

II. Respite Care: Child or adult care offering a period of relief for families with a disabled member or members.

A. Implementation: Families or individuals must request Respite Care through the Care Registry. It may take place in the following places:

1) In the home of the disabled person.

2) In the home of a licensed and approved temporary foster parent or family. The "host" parent or family may offer respite care to no more than two disabled persons at one time.

3) If the disabled person is in need of medical supervision, an approved medical facility may be utilized. This may include general hospitals, nursing homes, or private licensed facilities which meet the current licensing regulations of appropriate state agencies. Documentation of the person's medical needs must be obtained by the Department of Social Services and approval of the Home and Community Resource Program administrator must be gained before placement in the medical facility.

4) This service shall be provided only for the disabled family member(s) and does not include caring for non-disabled siblings except for in-home care. If any siblings are to be cared for other than the disabled person(s), the Care Registry coordinator will determine the additional charge.

B. Allowable time periods for Respite Care:

1) Respite Care shall be considered relief care lasting between 24 hours and two weeks except under special circumstances as approved by the Care Registry coordinator.

2) Respite Care for any individual shall not exceed four weeks within a given year except under special circumstances as approved by the Care Registry coordinator.

C. Program funds shall not be used to pay for Respite Care in the following situations:

1) For residents of state institutions for mentally or emotionally disabled persons.

2) For residents of community-based residential facilities which are already structured to provide relief hours for employed "responsible adults" or supervisors.

III. Family Aid: Relief lasting less than 24 hours in any one time period so that families can engage in the activities required by normal living (e.g. shopping, socializing, attending business meetings, keeping medical appointments, etc.). The Home and Community Resource Program will make this resource available to families who may have difficulty in obtaining "sitter" type services because a family member or members is/are disabled.

A. Implementation:

1) Families must contact the Care Registry coordinator to request the service. Unless the Care Registry has made the appropriate arrangements, the Family Aide will not be eligible to receive payment with program funds.

2) The Family Aide will be responsible for the care of every family member left in his/her charge. If any siblings are to be cared for other than the disabled person(s), the Family Aide must be so advised before being given the assignment and rates shall be set accordingly.

3) At the end of each care period, the Family Aide must submit to the Care Registry coordinator a written report which should include remarks about any significant events, incidents, etc., that occurred during that care period and which may prove helpful to other aides when and if the family receives services in the future. Such reports must be treated within the context of the rules of confidentiality and privacy so as to protect the rights of the service recipients.

4) Family Aid Services may be provided in the home of the disabled person or in the home of a DSS licensed and approved person or persons.

B. Allowable Time Periods:

1) The maximum time allowed for Family Aid service will be 24 hours per session. This may be overnight but shall not exceed the maximum time limit.

2) A recommended maximum of four sessions should be allowed per family per month. This may be adusted by the Care Registry coordinator based on individual needs and resources at a given time.

3) This service shall not take the place of day programming for the disabled child or adult.

IV. Day Care: Before and after school care for children, or full or part-day care for dependent disabled adults so their parent(s) or permanent caretaker(s) can pursue education, job training or employment.

A. Implementation:

1) Families must contact the Care Registry coordinator to request the service.

2) Care may take place in the home of the disabled person(s) or in the home of a DSS licensed and approved day care provider.

3) No more than two of the persons being cared for by the day care giver may be disabled.

4) This service shall not take the place of day programming for the disabled person.

5) Day care givers for disabled children may be recruited from among existing day care givers serving non-disabled children as well as from the community through standard recruitment efforts (via television spots, newspaper articles, etc.). Since there are at present no day care providers for disabled adults, such care givers shall be recruited from the community.

B. Allowable Time Periods: There shall be no time limit on the number of days or months during which day care is provided.

C. If there is an expressed need, existing licensed Group Day Care programs shall be considered an alternative where available and appropriate.

V. Homemaker Services: The primary functions of Homemaker Services are a) to provide care and supervision for persons with disabilities and other members of the family within the home when the adults regularly responsible are unable to provide care, and b) to provide training in proper home management. The Homemaker not only provides personal care but also insures that regular daily homemaking and housekeeping tasks are performed. This reduces the stress that the family would experience and, therefore, increases the chances that the family remain intact and that the disabled member need not be institutionalized. These services are also available to disabled adults who are living independently in the community.

A. Implementation:

1) The Homemaker's responsibilities may include any combination of the following:

a) Routine light household chores such as cleaning, cooking, marketing, meal planning, laundry and ironing, etc.

b) Personal care of other dependent person(s) as well as the disabled person(s).

c) Budgeting or money management.

d) Instructing the family member(s) or disabled individual(s) in how to perform homemaking duties more effectively and efficiently.

2) The Homemaker will be given, in writing, a list of specific responsibilies before each assignment.

3) The Homemaker may assume live-in responsibilities if there is no other responsible adult who is able to care for the dependent person(s) or the disabled individual(s) during the evening and night. This is allowable only if the Homemaker is providing daytime duties within the same household.

B. Allowable Time Periods:

1) The initial time period may not be for more than one month.

2) All requests for extension must be evaluated by the Care Registry coordinator and approved by the Home and Community Resource Program administrator. The lack of feasibility of other alternatives must be documented and specific goals for the extension period determined, with reasonable time limits established.

VI. Training: Caregivers for disabled persons (Respite Care providers, Family Aides, Day Care givers, Homemakers) may be recruited from existing caregivers for non-disabled persons or recruited fresh from the community at large.

A. Each caregiver must be approved by the Department of Social Services after successful completion of a training program before working as a caregiver for a disabled person.

B. Training programs shall be designed by the Department of Social Services in consultation with agencies and organizations serving the mentally, emotionally, and physically disabled.

C. The administration of the training program shall include recruitment, screening, and interviewing and providing follow-up support and training.

D. A portion of the Home and Community Resource Program money shall be set aside for basic training for caregivers. Caregivers may be paid while attending training sessions.

E. Follow-up training must be provided no less than once a year.

F. The training program may be contracted to another public or private agency but must be approved by the Department of Social Services in consultation with agencies and organizations serving the mentally, emotionally, and physically disabled.

G. This training and approval shall make the caregiver eligible to provide any and all of the services described in the Home and Community Resource programs, provided all other existing requirements for licensing and approval shall have been met.

The "Home and Community Resources Program: A Working Paper" and the respite-beds-in-institutions bill (reproduced on pp. 17-18) were sent to all Respite Care Network Coalition members and a meeting was called for January 17 to accept or revise both these courses of action.

Discussion at the January meeting, as well as an evaluation form which had been circulated earlier (see Appendix G, pp. 37-38), indicated that Coalition members were basically in agreement that the Montgomery County Department of Social Services seemed the logical generic service provider for respite care services. Both the Department of Social Services Chief of Family and Adult Services, Ann Bishop, and the Department of Social Services Supervisor of Day Care, Mary Lou Hurney, were members of the Respite Care Network Coalition. They met with the Project Supervisor and the Respite Care Network Coordinator several times to discuss the translation of the Working Paper into two funding proposals. A meeting was set up with Frank Sullivan, Maryland Department of Social Services, Chief of Purchase of Services Division, who also served as Chairman of the Community Based Programs Task Force of the Maryland Developmental Disabilities Council, and Philip Holmes, Associate Director of the Maryland Developmental Disabilities Council, to discuss procedures for permitting the Montgomery County Department of Social Services to operate Home and Community Resources Program as designed by the Coalition. These several meetings resulted in two grant proposals submitted by the Montgomery County Department of Social Services to the State Department of Social Services for funding under Developmental Disabilities and Title XX monies: (1) for a pilot project based on the Coalition Working Paper to provide a program for residents of Montgomery County who are seeking respite care for mentally and/or physically handicapped family members, and (2) for the training of caregivers in the respite care program. The direct-service proposal has been accepted and funded. The training proposal is currently pending.

Because both the Project Supervisor and the Respite Care Network Coordinator felt hopeful of success in having the Home and Community Resources Program funded--in no small measure due to the cooperation and enthusiasm for the project at both the state and local Department of Social Services levels--attention was turned to encouraging respite care programs in the District of Columbia and in Prince George's County. Both of these areas are currently served by Home Care Services for the Handicapped but D.C. and Prince George's County residents could not continue to be served by the Montgomery County Department of Social Services. Contacts were made; several different possibilities were explored. Temporary sponsorship for a respite program for District of Columbia residents was accepted by the Georgetown University Affiliated Center for Child Development. Prince George's County is at this moment exploring ways for replicating the services offered by Home Care Services for the Handicapped with collaboration and help from the Montgomery County Respite Care Network Supervisor and Coordinator.

TRAINING PROGRAMS FOR HOME CARE SERVICES CAREGIVERS

Throughout the course of the grant year, every six to eight weeks, a training session for Home Care Services caregivers was held (see Appendix E, pp. 31-35, for the agendas). As new volunteers joined the registry of Home Care Services family aides, they also joined the training sessions. Members of the Montgomery County Respite Care Coalition Network assisted by circulating information about the training workshops and, in some instances, by taking part themselves or recommending others to take part as trainers. Training was not difficult to organize. Most communities have capable and interested professionals; a training coordinator need only know the resources. The training sessions received very favorable reviews from those

attending. Following is an unsolicited letter from one of the caregivers who attended the workshops throughout most of the year.

May 30, 1977

I want to commend you on the series of seminars you organized for respite caregivers. Rarely have I seen a program deal so effectively with such a broad subject presented to an audience with widely differing backgrounds. More important than merely the exposure to facts about each handicapping condition was the chance to meet parents and professionals who are comfortable in dealing with disabled people. No matter how many Saturday mornings we met, our group could never deal with every potential situation that we may have to face, yet the series of seminars provided us with an agenda to prepare ourselves. I'm glad to see the amount of stress put on talking with parents and trusting their decisions. I feel that my work both in Home Care Services and in my professional future have benefitted from my Saturday mornings spent at MCARC. Thank you. Please let me know if I can be of any help in future seminars.

Yours,
Beth-Ann Bloom

LEGISLATION

H O U S E O F D E L E G A T E S

No. 1505

By: Delegates Kopp, Bell, Goldwater, Hixson, McCaffrey, and Avara
Introduced and read first time: February 21, 1977
Assigned to: Ways and Means

Committee Report: Favorable with amendments
House Action: Adopted
Read second time: March 28, 1977

CHAPTER -------

AN ACT concerning

Mental Retardation Administration - Respite Care Beds in Residential Facilities

FOR the purpose of reserving a certain ~~number~~ percentage of beds for respite care in certain facilities under the jurisdiction of the Mental Retardation Administration.

BY adding to

Article 59A - Mental Retardation
Section 19 (c)
Annotated Code of Maryland
(1972 Replacement Volume and 1976 Supplement)

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That new Section 19 (c) be and it is hereby added to Article 59A - Mental Retardation, of the annotated Code of Maryland (1972 Replacement Volume and 1976 Supplement) to read as follows:

Article 59A - Mental Retardation

19.

(C) ~~ONE-OUT-OF-EVERY--25--BEDS,--OR--~~ AT LEAST 2 PERCENT, BUT NOT TO EXCEED 4 PERCENT OF THE TOTAL BEDS IN ~~EACH-PUBLIC-FACILITY~~ ALL PUBLIC FACILITIES UNDER THE JURISDICTION OF THE ADMINISTRATION SHALL BE RESERVED, IN ACCORDANCE WITH RULES AND REGULATIONS PROMULGATED BY THE DEPARTMENT OF HEALTH AND MENTAL HYGIENE, FOR RESPITE CARE. HOWEVER, A PERSON WHO IS A RESIDENT OF A FACILITY ON JULY 1, 1977 MAY NOT BE DISPLACED IN ORDER TO IMPLEMENT THIS SUBSECTION, BUT INSTEAD, THIS SUBSECTION SHALL BE IMPLEMENTED THROUGH ATTRITION AS VACANCIES ARISE IN EXISTING BEDS. FOR PURPOSES OF THIS SUBSECTION, RESPITE CARE MEANS CARE FOR A PERIOD UP TO 28 CONSECUTIVE DAYS WITHIN ANY 12-MONTH PERIOD, MADE AVAILABLE FOR A MENTALLY RETARDED PERSON IN A PUBLIC FACILITY MAINTAINED BY THE ADMINISTRATION, IN ORDER TO PROVIDE RELIEF FOR PARENTS OR GUARDIANS WITH WHOM THE RETARDED PERSON ORDINARILY LIVES.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect July 1, 1977.

EXPLANATION: CAPTIALS INDICATE MATTER ADDED TO EXISTING LAW.
[Brackets] indicate matter deleted from existing law.
Underlining indicated amendments to the bill.
~~Strike-out~~ indicates matter stricken from bill.

Harriet O'Connor, the parent mentioned earlier who was responsible in large measure for stimulating the Respite Care Network Coalition's interest in introducing a bill in the 1977 session of the Maryland State Legislature, was made responsible for overseeing the progress of that bill. Through her efforts, Montgomery County Delegate Nancy Kopp introduced House Bill No. 1505 on February 21, 1977. The bill had five co-sponsors.

At the January 17 Coalition meeting, at another Coalition meeting held on March 15, and via telephone calls and written communication, the Respite Care Network Coalition members suggested people to contact for endorsements, recommended ways to improve the original "mock bill", and helped to formulate arguments for the testimony

presented at a public hearing on March 21 before the Maryland House of Delegates Ways and Means Committee. Several members of the Coalition submitted written testimony concerning the bill on behalf of themselves or their agencies to the Maryland Legislature. A Coalition member, Mary Akerley, represented the Montgomery County Respite Care Network Coalition at the House hearing, delivered the testimony, and answered questions from the delegates.

Information regarding respite care and its importance was circulated to legislators in the Maryland House and Senate as background to HB 1505. Endorsements were sought and received by the Montgomery County Special Education Schools principals, the Special Education Acting Supervisor, and the Montgomery County Council.

HB 1505 was given a rather lengthy hearing in the Maryland House of Delegates, was amended and given a favorable report. After passage in the House, HB 1505 was signed into law by Blair Lee III, in his capacity as acting Governor of the State of Maryland. An energetic and determined parent, with the help of the Montgomery County Respite Care Network Coalition, had been the force responsible for respite care legislation in the State of Maryland.

AN OPPORTUNITY FOR GROUP RESPITE CARE

The final item on the Coalition's "menu" of respite care services for the year was to be an opportunity for group respite care for families with developmentally disabled members. The first attempt was not a success. An after-school program for disabled children of working parents was planned, but although several hundred flyers were circulated through the schools describing the possibility of such a program if the need existed, and even though the Montgomery County Recreation Department was enthusiastic about joining the venture, few responses were received. The handful of requests that did emerge represented too wide a disparity in ages, needs, locations, and abilities to be able to set up a workable program. The seven parents who did call were helped individually to find solutions to their needs.

Happily, a second attempt at group respite care did prove successful. A two day weekend was planned which would provide respite for families and an enjoyable away-from-family-back-to-nature experience for developmentally disabled teenagers and adults. The Rockwood National Girl Scout Center in Potomac, Maryland, offered an ideal, close-by location, an interested and helpful staff, pleasant accomodations, nutritious and appetizing meals, and all at an attractively low cost. An October site visit by the Respite Care Network Coordinator proved delightful; plans got underway immediately for the outing. Because of the popularity of the Rockwood Center, available weekends were few. It was decided to opt for a summer experience in the hope that warm weather would mean greater possibility for a wider agenda of activities. As it happened, the last weekend in June was free; a respite care weekend seemed a most appropriate way to end the grant year. Coalition members who represented parent organizations published information in their newsletters. The Montgomery County Department of Recreation promised help with the program. The Respite Care Network Coordinator circulated information, answered parent calls, arranged for transportation and caregivers for the outing. Seventeen developmentally disabled teenagers and adults registered for a pleasant two day experience.

SOME RETROSPECTIVE OBSERVATIONS BY THE STAFF

1. Providing respite care alternatives need not be an expensive program.

2. But a community should not expect it to happen only through charity or the goodness of people's hearts.

3. The "menu" of respite care alternatives depends on the community and what's needed most.

4. Whether your community wants

   care in the home or care out of the home
   hourly, weekend, or week-long care
   day care, before or after school care, short-term foster care
   a respite care group home, dormitory, hotel, apartment, or camp site
   foster grandparents, students, teenagers, men, women, retired teachers or families to give the care
   beds in hospitals for medically involved persons
   crisis care,

   you will need a coordinator to receive those calls and get for the caller whatever services he needs or patch together what is possible.

5. To plan the spectrum of what your community needs, convening a

   coalition
   task force
   ad hoc committee
   or whatever you want to call it

   is the first step and will give your planning the diverse input it needs and your actions the collective clout they need.

6. But a single agency must be selected as the place to house the coordinator, assume responsibility for progress (at least temporarily), apply for funding (federal, state, local, public, or private) and do whatever the coalition says needs doing.

7. Individuals who are highly motivated and energetic may be just the workaholics you need to make it function. They should be welcomed right off the street if they look promising -- to join the coalition or work with the agency selected to sponsor the program.

8. There is plenty of professional expertise in most communities to call upon to help train the caregivers, often without charge. Training agendas are available from the Montgomery County Coalition and other sources as well. The main task is coordinating the training. Again, this need not be an expensive or difficult aspect of a respite care program.

9. You can work very hard at recruiting aides as caregivers -- by sending out dozens of news releases to dozens of newspapers and newsletter editors, by posting flyers at every college campus, by distributing information to every public library, to grocery stores, etc. -- or you can, with luck, do very little (one brief article in Anne's Reader's Exchange in the Washington Post,

to cite our experience) and end out with the same number of recruits! The massive publicity is good business because it informs and educates the community and plows the garden for future as well as present efforts. You might want to try every method once and keep track of results. Then do only what yields the best crop. Obviously, too, where you do your recruiting may be dictated by the kind of people you are looking for -- students, retired persons, housewives, whoever.

If you try public service announcements over radio or TV, be ready for lots of phone calls yielding few real recruits. With only 60 seconds at best to explain your needs, there's a lot of room for the people tuned in to miss half of what's said, be misled or misinterpret the information. They'll call, but they won't quite know what for.

10. Individuals and families need to be helped to learn how to use the program and to be realistic about what it can and cannot provide. It takes time for families to build trust in a service. But word spreads, and if the quality of the care given is high, the program will grow -- slowly but surely.

11. The quality of the coordinator who connects the families with the caregivers is crucial. She/He must be able to listen, understand, ask the right questions, deal with difficult situations, pick good caregivers, help parents feel comfortable about asking for help, keep useful records, and -- above all -- be knowledgable about handicapping conditions, familiar with the people who have them, and informed about other resources they might need.

12. WE WISH YOU LUCK! WE'RE AVAILABLE TO HELP IF YOU NEED US.
Call Cory Moore, Peg Morton, or Cindy Love at (301) 949-8140.

AFTERWORD

Anyone who works in people-helping fields, as all of our Coalition members do, knows that keeping track through daily logs or records of what one accomplishes in the day's crush of activities is often the last straw and the first activity to go. And yet those logs and records tell tales which would otherwise pass unnoticed. This record of a year's work and accomplishments is a ringing reminder to those involved that it was indeed a year of hard work on the part of many people and that their work did cause things to happen. The Coalition was a splendid group of thoughtful and caring people who agreed on goals and worked together to achieve them. In one year's time they translated surveys, plans, recommendations and proposals into real services for real people.

And meanwhile, the Coalition's sister project, Home Care Services for the Handicapped, was reaching more and more people: The number of families requesting care doubled to over 180, the number of aides providing care octupled to 48, and the number of hours of care provided quadrupled to an average of 350 each month. In a peak month, out of 97 requests for care, the coordinator was unable to fill only five.

What these numbers mean in human terms -- relief from stress, help in an emergency, a chance to regain composure, renewal of relationships, refreshment from fatigue -- only the families can tell. But we like to think that the quality of some lives was improved. That was our unmeasurable goal.

Peg Morton, Project Supervisor

APPENDIX A: COALITION MEMBERS

(starred names are those who served on the subcommittee for legislation and subsidized respite care)

* Mary Akerley, Centers for the Handicapped
Ann Bishop, Department of Social Services, Division of Family and Adult Services
Eugene Chiaverini, Department of Social Services, Division of Child Welfare
* Ron Coleman, Great Oaks Center
Bea DiMichael, Centers for the Handicapped
Mary Alice Fox, Montgomery County Health Department, Division of Infant and Child Services
Rosemary Garr, later replaced by Betty Whitney, Montgomery County Public Schools, Division of Special Education
Iris Gordon, Mental Retardation Administration, Montgomery County Continuum of Care Supervisor
* Mark Gottlieb, Montgomery County Department of Health Systems Planning
* Jane Gridley, Montgomery County Association for the Advancement of the Physically Handicapped
Harriet Howard, Montgomery County Public Schools, Division of Special Education Acting Supervisor
Mary Lou Hurney, Department of Social Services, Division of Day Care
Linda Jones, Montgomery County Department of Recreation, Special Programs
Judy Levy, Montgomery County Association for Children with Learning Disabilities
Anne Maysak, Parent
Helene Milman, Association for Children with Social and Emotional Problems or Troubles
Suzanne Misner, Montgomery County Chapter, National Association for Autistic Children
Gail Nachman, formerly Great Oaks Center, currently Central Maryland Regional Direction Center
* Harriet O'Connor, Parent
Lucille Rattner, replaced by Leona O'Reilly, Montgomery County Association for Hearing Impaired Children
Meg Riesett, Montgomery County Community Coordinated Child Care Council
Harriet Sommerwell, Montgomery County Mental Health Association
Marit Thorson, Office of Human Resources
Ernestine Tilghman, replaced by Paul Wang, Great Oaks Center
Becky Viezas, Montgomery County Public Schools, Pupil Placement
Peter Zeibell, Montgomery County Health Department

Cindy (Beck) Love, Home Care Services for the Handicapped
* Peg Morton, Montgomery County Association for Retarded Citizens and Project Supervisor
* Cory Moore, Montgomery County Association for Retarded Citizens and Coalition Coordinator

APPENDIX B: CHILD CARE SURVEY

Family Information

	Age	Sex
1. Handicapped family member	_____	_____
2. All persons living at home	_____	_____
	_____	_____
3. Is the total income level of the family:	_____	_____
	_____	_____
below $10,000___ $10,000-$20,000___ $20,000-$30,000___	_____	_____
$30,000-$40,000___ $40,000-$50,000___ Over $50,000___		

4. Describe the handicap:_____
5. What program does the handicapped person from your family attend?
   School___, Employment___, Workshop___, Residential___, Other_____
   If residential, how often does he/she come home?_____

Use of Care

If you have used IN THE HOME care or OUTSIDE THE HOME care, please fill in the following information as best you can. If you do not use the care regularly, but only in emergencies, put an "E" in the "How often" space provided.

CARE IN THE HOME

	How Often? (times per week, etc.)	Pay (specify hourly, weekly, etc.)
1. neighbor/friend	_____	_____
2. sitter (untrained).	_____	_____
3. sitter (trained).	_____	_____
4. nurse (specify_____)	_____	_____
5. live-in help	_____	_____
6. hired daily help	_____	_____
7. other_____	_____	_____

8. relative:

Relationship	Sex	Live-In		
_____	____	_____	_____	_____
_____	____	_____	_____	_____
_____	____	_____	_____	_____
_____	____	_____	_____	_____

9. Please state why you chose the kind(s) of care you did:_____
   _____

OUTSIDE THE HOME

Questions 6, 7 and 8 are for relief care only. Do not check for residential living or illness.

	How Often?	Pay
1. friends/neighbors house	_____	_____
2. relatives house	_____	_____
3. sitter (untrained)	_____	_____
4. sitter (trained)	_____	_____
5. recreation program	_____	_____
6. institution	_____	_____
7. nursing home	_____	_____

	How Often? (times per week, etc.)	Pay (specify hourly, weekly, etc.)
8. hospital		
9. camp: day		
overnight		
10. relief care family (regular family which takes handicapped people into their home for brief periods on paying basis)		
11. relief care group home (3 to 8 children/adults in agency maintained home, with houseparents or assistants)		
12. temporary foster care		
13. other_____		

14. Please state why you chose the kind(s) of care you did:_____

_____

15. I would need transportation to and from care. Yes___ No___

16. What would you use as a back-up if the resource you use was not available?

_____

If you use care at any of the times listed below please state how often. If you could use care either on a regular basis or for relief or emergencies, please check the appropriate blank.

	How Often? (times per week, etc.)	Might use in case of need
1. before school		
2. after school		
3. while working		
4. for doctor or other appointments		
5. emergency		
6. evening out		
7. overnight		
8. weekends		
9. vacations		
10. during residential school holidays		
11. in my home while I am there (lifting, bathing, supervision while I do housework)		
12. other_____		

13. I prefer care: in my home___ outside my home___ depends on the situation_____
Please describe the situation_____

_____

I have never used relief care because:

1. I never needed the service ____
2. Unaware of service available ____
3. I cannot afford service ____
4. Do not feel care available is adequate ____
5. Care was unavailable when needed ____
6. Child too difficult for others to handle ____
7. Child would not adjust to care by others ____
8. I would worry too much about leaving the child ____
9. The type of care I need is unavailable ____

Please describe_____

_____

COST OF CARE

A. The most I would be able to pay: Hourly_____ Daily_____ Weekly_____

B. I cannot afford to pay for services but would be willing to exchange services with other families that I: Know well____ Are members of an organized sitters group___

SPECIAL NEEDS

Personal Care: The handicapped person in our home:

1. Requires special equipment . . . . . _____
   Please describe_____
2. Requires frequent medical attention . . . . . _____
   Please describe_____
3. Requires special training or skills to care for him . . . . . _____
   Please describe_____
4. Requires special diet . . . . . _____
   Please describe_____
5. Requires special handling because of behavior . . . . . _____
   Please describe_____
6. Please describe any other special needs_____
7. Is able to walk alone . . . . . _____
8. Is able to toilet himself . . . . . partially_____completely_____
9. Is able to dress himself . . . . . partially_____completely_____
10. Is able to bathe himself . . . . . partially_____completely_____
11. Is able to feed himself . . . . . partially_____completely_____
12. Is able to verbalize needs . . . . . partially_____completely_____
13. Requires the following amount of supervision in his activities:
    minimum___medium___maximum___
14. Requires housekeeping and/or personal care assistance only:
    minimum___medium___maximum___

Any Comments:_____

_____

_____

_____

APPENDIX C: CHILD CARE SURVEY COVER LETTER

Dear Parents:

All families find themselves in need of child care--in times of crisis, to go to work, to go to a movie or just to have some time off from the demands of caring for a family. Families with a physically, mentally or emotionally disabled child or adult in their home have similar needs but often have a difficult time finding the type of care they need when they need it. Other families, for one reason or another, are hesitant to use the care that is available, and some families need more "relief" than established child care services offer.

In order to help relieve what we feel is a shortage of help for families with handicapped members, a coalition of parent organizations and community agencies in Montgomery County have joined together to draw up a survey. We would like to know what kinds of child care services families are currently using as well as what services they would like to have available. We hope the information gained from the survey will be used to improve and expand present child care services and to plan new services based on the needs of the families.

By filling in this survey as completely as possible you will be helping to make this study reflect the true needs of the families in our community. All information obtained in this survey is anonymous. You do not need to include your child's name or your name on the form. If you do have any questions about the study or present child care services you may call _____ at _____.

Sincerely,

APPENDIX D: CHILD CARE SURVEY RESULTS

1. GENERAL INFORMATION

Families were selected by six parent organizations (Association for Children with Social and Emotional Problems or Troubles, Centers for the Handicapped, Montgomery County Association for Retarded Citizens, Montgomery County Association for the Advancement of the Physically Handicapped, Montgomery County Chapter of the Society for Autistic Children and the Spina Bifida Association) to represent 50 children of various ages from preschool through adult, and various kinds of handicapped conditions, most of which were severe. 25 of the children were described as retarded, 12 as physically handicapped, 5 as severely, multiply handicapped and 8 as emotionally disturbed or autistic. 19 families were interviewed in person; 25 were contacted by phone and mailed a questionnaire to which they responded, making a total of 44 families surveyed with 50 children.

32 of the children were male and 18 female. 45 live with both parents, 5 with a single parent. 33 attend special schools, 9 attend a sheltered workshop, 7 are in residential programs. One attends a regular school.

Family Income Level:

Below $10,000	1
$10,000 to 20,000	17
$20,000 to 30,000	13
$30,000 to 40,000	9
$40,000 to 50,000	3

Ages:

1 through 5	8
6 through 12	21
13 through 20	13
21 through 30	8

2. CARE IN THE HOME

By:	Frequently	Occasionally	Rarely	Not at All
Neighbor/friend	6	10	6	22
Sitter (untrained)	7	11	3	23
Sitter (trained)	1	7	4	32
Nurse	0	0	5	39
Live-in help	1	0	3	40
Hired daily help	0	2	3	39
Relatives				
Siblings	14	8	1	22
Grandparents	0	6	5	33
Other	1	1	0	42

3. CARE OUTSIDE THE HOME

In home of:	Frequently	Occasionally	Rarely	Not at All
Neighbor/friend	3	1	11	29
Relative	0	5	8	27
Sitter (untrained)	1	1	1	41
Sitter (trained)	1	0	8	34
Institution	1	0	6	37
Nursing Home	0	0	0	44
Hospital	0	0	0	44

Camp - overnight, current use	14
overnight, in past but no longer	14
Relief Care family	0
Relief Care Group Home	0
Foster Care	0
Other	0

4. HOW OFTEN ARE FAMILIES USING CHILD CARE OF ANY KIND IN ORDER TO GO OUT?

Not at all	5
Emergencies only	4
Rarely (less than 1 x per mo.)	6
Occasionally (1 to 2 x per mo.)	11
Frequently (1 x per wk. or more)	17
Other (can't find anyone to relieve live-in maid)	1

5. WHERE CARE IS PREFERRED:

In the home	20
Outside the home	5
Depends	13
No response	6

6. WHAT WOULD YOU USE AS BACK-UP CARE IF YOUR CUSTOMARY CHILD CARE WERE UNAVAILABLE?

Don't know	25
Friend/neighbor	6
Relative	3
Trained sitter	6
Institution	1
No response	3

7. FOR WHAT PURPOSE WOULD YOU LIKE TO HAVE RELIEF CARE MORE READILY AVAILABLE?

Emergencies	21
Vacations	25

8. FAMILY HAS NEVER USED RELIEF CARE BECAUSE....(Relief care was interpreted to mean specialized care given by agencies, something different from the family's customary source of child care.)

Never needed the service	7
Unaware of service available	6
Cannot afford service	5
Do not feel care available is adequate	3
Care unavailable when needed	11
Child too difficult for others to handle	6
Child would not adjust to care by others	2
Parents would worry too much about leaving the child	5
Type of care needed unavailable	4

9. AMOUNT PAID FOR CHILD CARE:

The majority of families paying neighbors/friends, untrained or trained sitters are paying $1.00 per hour. Some pay up to $2.00 per hour. The few siblings who are paid receive less than $1.00 per hour. Several families receive sitting services free, from staff members of their children's schools, friends, neighbors and, of course, siblings or grandparents.

The going rate for 24 hour care appears to be $20.00 to $25.00. 13 families suggested a weekly rate which they would be willing to pay; there was no agreement, with a range from $20.00 to $150.00.

10. FAMILY SITTING EXCHANGE:

Would exchange with families they know well	7
Would exchange with members of organized sitting group	6
Depends on the situation	3
Would not exchange	23

11. SPECIAL NEEDS:

1. Requires special equipment

Wheelchair	1
Wheelchair plus other aid	6
Other than wheelchair	3

2. Requires medication 9

3. Requires caretaker with special training or skills: 13

Previous orientation to handicap (6)
Ability to love (7)

4. Requires special diet 5

5. Requires special handling because of behavior 18

6-12. Requires total or partial assistance with walking, toileting, dressing, bathing, feeding 25-30

Feeding	14
Unable to verbalize needs	12

13. Requires supervision:

Minimum	11
Medium	11
Maximum	12

APPENDIX E: TRAINING SESSIONS

THE CARE OF THE HANDICAPPED
Saturday, October 2, 1976

Agenda

9:30 - 10:30	Orientation What are developmental disabilities? How do families and communities cope with their handicapped members? One community's answer: IN THE MIDDLE OF THINGS (a slide presentation) Families' needs for options	Mrs. Peg Morton Director of Mont. Co. Assn. for Retarded Citizens Family and Community Services
10:30 - 11:45	Parents and Children Rotating groups of participants talk with mothers and their children Each mother's experience as the parent of a handicapped child	
11:45 - 12:30	Lunch Break - Bring your own! Coffee, tea, cold drinks, doughnuts available	
12:00 Noon	Optional Film	
12:30 - 2:00	A Medical Overview Characteristics of developmental disabilities Handling medical problems: seizures, medication, emergencies, first aid When to call a doctor	Dr. Mary Alice Fox Pediatrician
2:00 - 2:30	Physical and Orthopedic Care Bathing, dressing, toileting, feeding Use of special equipment: braces, wheelchairs, etc.	Janie Russell Physical Therapist
2:30 - 3:45	Managing Behavior Discipline, positive ways to handle children Encouraging independence Helping children feel comfortable with a new person or new surroundings Special considerations for handicapped adults	Dr. Mary Robinson Pediatric Psychologist
3:45 - 4:30	How can you help? Introduction to Home Care Services for the Handicapped The role of day care mothers and foster parents Your evaluation of the training session	Cindy Beck Coordinator of Home Care Services

THE CARE OF THE HANDICAPPED
CARING FOR THE ADOLESCENT AND THE ADULT
Saturday, November 13, 1976

Agenda

9:30 - 10:15	The Care of the Handicapped Adolescent A Description of the Special Needs of People Who Are Autistic	Mrs. Suzanne Misner Former President of the Montgomery County Chapter, National Society for Autistic Children
10:30 - 11:00	Film Presentation: IT'S THEIR WORLD TOO (PCMR film - participants in the film are residents of Montgomery County and Northern Virginia)	
11:00 - 11:45	The Care of the Handicapped Adult	Mr. Rob Romagna Director, MCARC Developmental Center
11:45 - 12:00	Wrap Up - Evaluation	

THE CARE OF THE HANDICAPPED
Saturday, February 26, 1977

Agenda

Morning Session:	Introduction to Handicaps and Respite Care
9:15 - 9:45	Group Introductions
9:45 - 10:15	What are Developmental Disabilities? Cindy Beck, Home Care Services Coordinator
10:15 - 10:50	Families of the Handicapped--attitudes, problems, the need for respite care, how to make respite care carefree for parents Ernestine Tilghman, Social Worker, Great Oaks
10:50 - 11:00	Break
11:00 - 12:00 noon	Medical Problems and Physical Care Jeanne McArdle, Public Health Nurse, Great Oaks
12:00 - 1:00 p.m.	What To Do When You're Alone with the Person You're Caring For--getting to know each other, recreation and play, discipline, behavior problems Cindy Beck, Home Care Services Coordinator Ernestine Tilghman, Social Worker, Great Oaks Panel of Home Care Services Caregivers
1:00 - 2:00 p.m.	Lunch
Afternoon Session:	Physical Handicaps - Spina Bifida, Cerebral Palsy, Muscular Dystrophy, Multi-handicaps
2:00 - 4:00	Jeanne McArdle, Public Health Nurse, Great Oaks Cory Moore, MCARC, Respite Care Coordinator Carole Shea, Parent Jane Erickson, Parent Patricia Roth, Nurse, Muscular Dystrophy Association Adrienne Fisher, Parent

CARE FOR THE HANDICAPPED
Saturday, March 19, 1977

Agenda

9:15 - 9:45	Group Introductions
9:45 - 11:00	Recreation and Leisure Activities with Developmentally Disabled Children Ellen Gotow, Physical Therapist Ilse Sugarbaker, Physical Therapist Ronnie Devoney, Administrative Assistant, MCARC Preschool
11:00 - 11:15	Break
11:15 - 12:00 noon	Recreation and Leisure Activities with Moderately and Severely Retarded Adults Rob Romagna, Director MCARC Developmental Center

CARE FOR THE HANDICAPPED
Saturday, April 16, 1977

Agenda

9:15 - 9:30	Group Introductions
9:30 - 10:30	Basic First Aid Around the Home Susan Hilliard, Nursing Student, University of Maryland
10:30 - 10:45	Break
10:45 - 12:00 noon	Care of the Chronically Ill and the Elderly Joanne Livingston, R.N., Montgomery County Health Department, Adult and Geriatric Services

CARE FOR THE HANDICAPPED
Saturday, May 21, 1977

Agenda

9:15 - 9:30	Group Introductions
9:30 - 10:45	The Hyperactive Child Encouraging a Positive Self-Image in the Individual with a Handicap Walter Hillabrant, Psychologist
10:45 - 11:00	Break
11:00 - 12:00 noon	Encouraging Language Development - The Hearing Impaired Sue Gwyn, Speech Pathologist

CARE FOR THE HANDICAPPED
Saturday, June 11, 1977

Agenda

9:30 - 10:00	Introduction to Training Program How do Families Cope with Their Handicapped Members? How You Can Help	Cory Moore Coordinator, Mont. Co. Respite Care Coalition
10:00 - 11:30	A Medical Overview Characteristics of Developmental Disabilities How to Handle Medical Problems	Jeanne McArdle Public Health Nurse
11:30 - 12:30	Lunch Break - Bring your own! Coffee, tea, cold drinks, and doughnuts provided	
12:30 - 1:00	Physical and Orthopedic Care Bathing, dressing, toileting, feeding Special equipment	Janie Russell Physical Therapist
1:00 - 2:30	Parents and Children Parents will discuss their experiences; children will be present Handicaps include mental retardation, blindness, spina bifida, cerebral palsy, autism, seizures	Carole and Denise Shea Mindy and Lisa Schwedt Ruth and Chuckie Fitzgerald Susan and Kristie Jones Zena and Paul Stoller
2:30 - 2:45	Coffee Break	
2:45 - 4:00	Managing Behavior Discipline Helping children feel comfortable with a new person or new surroundings	Larry Harper Psychiatric Social Worker
4:00 - 4:30	Home Care Services Procedures for joining the team of helping caregivers	Cindy Beck Love Home Care Services Coordinator

APPENDIX F: WHAT ARE OTHER STATES DOING ABOUT RESPITE CARE SERVICES?

Pennsylvania: The Family Resource Services Program, provided through an act of the state legislature and administered by the Office of Mental Retardation/Mental Health, provides any service necessary to a family to enable them to keep their retarded child at home. Types of services offered include respite care in a temporary residence for the retarded family member, homemaker services, and family aides within the home trained, approved, and paid by the County Mental Health/ Mental Retardation Office.

Washington: A "care services" bill approved by the Washington State Legislature in 1975, with first year appropriations totaling $760,000, is helping families keep their developmentally disabled children at home by providing needed services at no cost to the parents. Temporary in-home care for respite or emergencies is one service available. This Home Aid Program is under the jurisdiction of the Department of Social and Health Services.

Minnesota: The 1975 Minnesota Legislature has helped a family provide or purchase services for their retarded child at home that the child would otherwise receive only in a state hospital or community facility. The family may receive a parent subsidy up to $250 a month, depending on the needs of the individual child, for services including child care or parental relief. Families are selected by the State Department of Public Welfare with assistance from the Minnesota Association for Retarded Citizens. Appropriations of $300,000 followed the legislation.

Ohio: The Comprehensive Respite Care Program, funded through the Ohio office of the Developmental Disabilities Planning and Advisory Council, provides respite care facilities, sitters, homemaker services and home training services.

Connecticut: The Hartford Regional Center respite program trains respite families licensed by the Connecticut Department of Health, Office of Mental Retardation, to provide respite care within their homes. A California Regional Center for the Developmentally Disabled has planned a similar service.

Kansas: RISC (Reduce Institutionalization of Special Children) is a program in Johnson County, Kansas, which makes available temporary foster homes for placement for a weekend or up to four weeks a year. Foster parents are trained by the Johnson County Mental Retardation Center and licensed by state and local authorities.

APPENDIX G: RESPITE CARE COALITION EVALUATION QUESTIONNAIRE

RESPITE CARE PILOT SURVEY

1. Did you feel the pilot survey submitted to families regarding their child care practices was designed well enough to elicit the information desired?

2. Did you feel there was important information it did not solicit? If so, what?

3. Was the target population adequately represented for purposes of our coalition?

4. Were you in agreement with the majority view of the coalition not to solicit a larger sampling?

DISSEMINATION OF FACT SHEET ABOUT WHERE FAMILIES WITH DEVELOPMENTALLY DISABLED MEMBERS CAN CALL FOR CHILD CARE

The fact sheet, "Someday I May Need to Know Places to Call For Child Care", has been circulated to the three Montgomery County Public Schools for the moderately retarded, the MCARC Developmental Center, Great Oaks, the Centers for the Handicapped Workshop, MCARC Preschool, Centers for the Handicapped Preschool, Public Health Nurses, Vocational Rehabilitation Office, Social Services and interested parents and professionals on MCARC mailing list. A total of 1500 copies has been distributed.

1. In your opinion, was this sufficient distribution?

2. When the revised fact sheet is available for circulation, are there other places you would suggest for distribution?

PRIORITY RATING OF KINDS OF RESPITE CARE TO OFFER

Please rank in order of importance the kinds of respite care you think should be offered ("1" would indicate highest priority, "2" next highest, etc.):

In-Home

Less than 24 hours _____

More than 24 hours _____

Homemaker _____

Group Respite Care House _____

Other (please list)

_____ _____

_____ _____

_____ _____

Out-of-Home

After school _____

Overnight or weekend _____

One week _____

Two weeks _____

One month _____

More _____

PHILOSOPHICAL ORIENTATION AND FUTURE DIRECTIONS

Do you feel that respite care — care in home, care out of home, after school care, temporary foster family care — is a specialized service which should be given by a specialized agency concerned with handicapped children? _____

OR, do you feel that respite care -- care in home, care out of home, after school care, temporary foster family care — should be an extension of the sources for non-handicapped persons and should be offered by the public/private agencies already concerned with such services? _____

Ideally, what public or private agency or agencies would you like to see provide the various forms of respite care in our "menu" of respite care services?

Can you suggest any funding sources?

Have you additional suggestions for actions not yet taken or contacts not yet made?

INVOLVEMENT OF COALITION MEMBERS IN DECISION-MAKING

1. Do you feel you've had sufficient voice in deciding next-steps to be taken? _____

2. Do you feel a coalition approach to accomplishing goals is useful or wasteful? _____

Signature _____

I prefer to remain anonymous _____